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# Living Wills: Speak Now and Forever Rest in Peace

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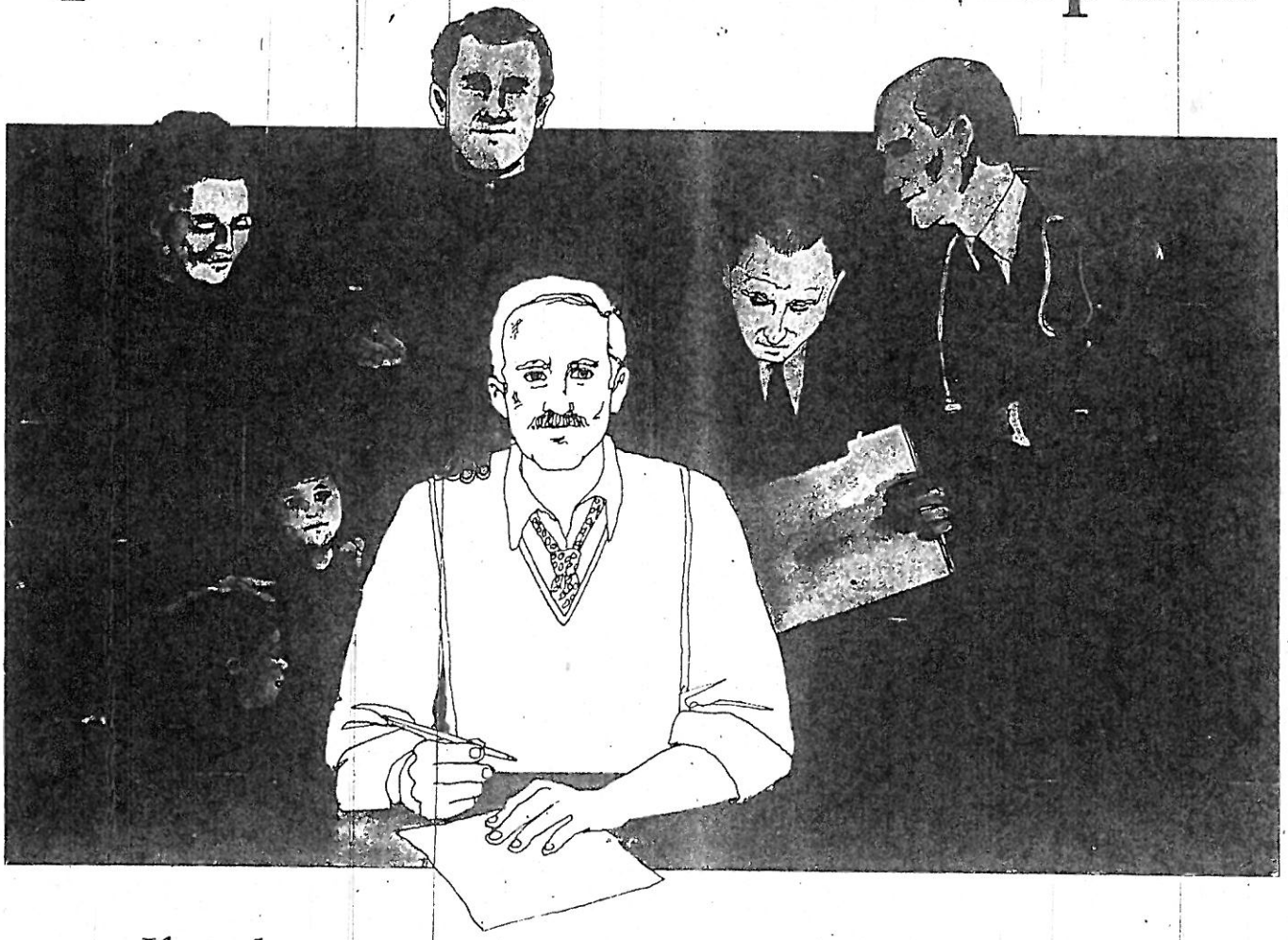

*If you became comatose tomorrow and showed little hope for full recovery, who would decide your future? Experts agree it would be a shame if it couldn't be you.*

Kathleen A. Cahalan

"My father was 101 years old when he died. In the last year of his life, he was placed in a nursing home and contracted pneumonia five times, each time being rushed to the hospital and given intravenous antibiotics that pulled him through," says Stephen Schmidt of River Forest, Illinois. "My sister and brother and I kept thinking Dad would die, but each time he recovered and was sent back to the nursing home.

"He had become senile, and so it was impossible to have him sign any kind of document and speak to the doctors, but for the previous twenty years he had talked about his desire and readiness to die. After the fifth bout of pneumonia and fifth trip to the hospital, my brother drafted a document, which my sister and I signed, stating that if the pneumonia were to reoccur we did not want Dad taken to the hospital and treated. We had it notarized and gave it to the nursing home and doctor.

"Dad contracted pneumonia not long after that and died three days later. We were very fortunate to have a facility and doctors and nurses to cooperate with us. I'm not sure what would have happened if they didn't."

If you were in a coma and could make no decisions about your health-care treatment, what would you want done for you? Would you

want life-sustaining treatment even if there were little chance of your recovery?

Many Americans seldom think concretely about what they would want for themselves in such situations. Furthermore, many are not likely to pause to consider how they would make hard choices for others who may be incapacitated by serious illness.

## Get it in writing

After a three-hour "Nightline" program entitled "Who Lives, Who Dies, Who Decides?" in September 1986, 2000 viewers were polled on whether a competent adult had the right to refuse life-sustaining medical treatment even if his or her doctor or family disagreed. Ninety percent strongly favored the patient's rights. Seventy-nine percent strongly agreed that a patient's potential quality of life should be considered in determining whether life-sustaining technology should be used. Seventy percent strongly agreed that families rather than the courts should decide whether to use life-sustaining treatment for incompetent patients. And in a 1986 American Medical Association poll, 1100 of the 1500 questioned said they favored withdrawing life-support systems, including food and water, from hopelessly ill or irreversibly comatose patients if they or their families requested it.

A living will is a signed, dated, and witnessed document allowing a person to make his or her wishes about life-sustaining treatment known so that both the family and physician can make appropriate decisions if the patient becomes incapacitated and unable to communicate. The living will was developed in 1967 by Concern for Dying, an advocacy group for patient rights. The largest organization of its kind, Concern for Dying has 250,000 supporters in the United States and has distributed 8 million living wills. The organization believes that living wills are enforceable in all states under the common-law right to bodily self-determination and the constitutional right to privacy.

"Our goals have been to educate the public and the professionals of the rights of patients and to make advance directives [living wills] available," says Mary Meyer, executive assistant of Concern for Dying. "In the past, people thought that signing a living will would mean they would be abandoned, but lately we have seen more people and health-care professionals supporting advance directives. The elderly in particular are more concerned about the quality of life in nursing homes and are more willing now to say no to such treatment for themselves."

**The Catholic Church teaches that life is not to be prolonged at all costs or by every extraordinary means.**

Since 1977, most states have passed legislation that makes a specified living will legally binding. The Society for the Right to Die, another patient-advocacy group in New York, has been active in shaping living-will legislation. Between 1976 and 1987 there were 39 living-will laws enacted. These authorized adults to execute an advance declaration stating that, in the case of terminal illness, life-sustaining procedures would be withheld or withdrawn.

Yet not all share this enthusiasm over living wills. Richard Doerfinger, associate director for Policy Development for Prolife Activities at the Office of the National Conference of Catholic Bishops, warns that living wills may, for some persons, replace communication with family and physicians. "A legal document like a living will may or may not be useful; and even at its best, it may be a poor substitute for good communication with your doctor and family," he says. Doerfinger is not confident that any living will is capable of dealing with decisions at the end of one's life. He suggests that a better alternative is to speak with your doctor about what you want and what you don't want.

## Against all odds

In March 1986, Jackie Cole of Baltimore, Maryland suffered a massive stroke that left her in a coma and near death. At the time of her stroke, Jackie declared to her daughter, "Christina, I think I'm having a stroke." And before she became unconscious, she said, "I don't want to live this way." Prior to the stroke, Jackie and her husband, Harry, had discussed life-support systems because Jackie's mother suffered from a nonmalignant brain tumor and had become quite disabled. Jackie had told her husband at that time, "I don't want to live like this."

Harry, a Presbyterian minister, was told that if Jackie survived she would never regain consciousness and would be in a persistent vegetative state. After 41 days, Harry petitioned the court for permission to disconnect Jackie's life-support system. Even the attorney representing Jackie requested that the life support be stopped. The odds of recovery were from 1 in 100,000 to 1 in 1,000,000; and even if Jackie did recover, medical authorities said she would have severe brain damage. The judge denied the request, stating that not enough time had

elapsed.

A week later, while preparing to transport Jackie to a long-term nursing facility, Harry witnessed a miracle: Jackie opened her eyes. Now nearly four years later, Jackie is almost fully recovered.

Even though Harry knew how Jackie felt about life-sustaining treatment, he says, "It didn't influence my decision that much. My decision was based on the circumstances of her illness, the hopelessness of the situation, and my belief as a Christian that Jackie would have a better existence beyond this comatose state and that we, the doctors and myself, were thwarting that."

Perhaps, surprisingly, Jackie's miraculous recovery has not changed Harry's feelings about his decision. "Jackie's waking up was totally unexpected, and it made the whole incident of the coma and stroke and the trial and court decision a moot point. I felt that my decision at the time was the right and fitting moral response, and I have no regrets about making it. I thought it out, consulted others, and felt okay about it. But Jackie's recovery I viewed in miraculous terms, as an act of deliverance."

Harry adds, "The whole process was a matter of discerning what God's will was for Jackie and myself. In the beginning it was a very slow process of accepting what happened; but as the crisis continued, it was as if God were going to bring something positive out of it that we could all learn from and grow from. At that point I believed Jackie would die and that from her death something redemptive would come to us. This, above all, helped me make the decision to stop the life-support systems. Yet, even in making this decision, I never lost hope that Jackie might come out of the coma. But I had to act and make a decision and believe that God would use that decision for whatever his purposes were."

The Coles' experience indeed is an extraordinary one, and they are reluctant to dole out advice to others. "Every person's situation is quite individual and personal," Harry says. "Jackie and I don't feel competent to pass judgment on others. I know most people don't end up with the happy ending that we did; but I believe that our experience and the process I went through to come to my decision can help others in a similar situation."

Instead, Harry suggests that persons facing the difficult moral decision of removing a loved one from a

**If you have strong feelings about treatment, consult a lawyer and put them in writing.**

life-support system look at four different levels of the situation.

"The first level you must deal with are the medical facts of the case—what caused the stroke and how deep is the coma? The medical facts in Jackie's case indicated that it was hopeless. The second level, the emotional level, is where a person can ask himself or herself, 'How do I feel about this loved one being in a persistent vegetative state? How do I think they would feel? How do other loved ones feel?'

"The third level constitutes a spiritual examination in which a person asks, 'What is God saying to me? How can I respond in this situation?' And finally, there is a fourth level of practical considerations, in which financial considerations are an important part."

## Out of the ordinary

The Catholic Church has a rich history that can help Catholics today make decisions regarding life-sustaining treatment. A main point that has emerged in this tradition over several centuries is the distinction between ordinary and extraordinary means of medical treatment.

The question of one's moral obligation to receive medical treatment, even if this treatment should prove to be futile, was part of the theological discussions of the sixteenth century. At that time the question was whether allowing oneself to die without medical treatment was an act of suicide.

The teachings on this question by Francisco di Vittoria, a Spanish Dominican, have provided a framework that endures today in discussions of medical treatment. Francisco taught that Christians are morally obligated to prolong life; but because in some situations this may prove too burdensome, treatments or medications are not required if there is strong doubt that they would be of help, if they prove to be ineffective over time, or if a grave burden is required for such treatment.

In this last case, the definition of grave burden is of central importance. Included in Francisco's discussion of grave burdens are physical, psychological, and economic factors, which he brings to bear upon the distinction between ordinary and extraordinary means. The distinctions Francisco made provided a framework within Catholic moral teaching that is still helpful today.

At first, ordinary means were understood as common means—those easy to obtain and available to anyone. Extraordinary means were those that were difficult to obtain because of expense or inconvenience. For example, consulting a physician and receiving appropriate medication for an illness was seen as ordinary; whereas, traveling across

the Atlantic to receive a rare cure or surgery would have been extraordinary.

But in time these terms took on an ethical meaning, that is, ordinary means came to be seen as morally obligatory and extraordinary means came to be seen as morally optional. The definition of grave burden, consequently, came to be associated with morally optional means of treatment. If, for example, traveling across the ocean to seek medical treatment would involve an extraordinary financial burden for a poor farmer, he would not be morally obligated to seek such treatment.

But times have changed, and many medical treatments once seen as extraordinary are now common. Respirators, IVs, and blood transfusions are all readily available in modern hospitals. It is therefore appropriate to ask, in a case that might involve oneself or another, whether their use would be effective in the long run or if they would involve too great a burden.

The Vatican's 1980 *Declaration on Euthanasia* states: "The distinction of ordinary/extraordinary is good but may be less clear today. In any case, it will be possible to make a correct judgment as to the means by studying the type of treatment to be used, its degree of complexity or risk, its cost, and the possibilities of using it and comparing these elements with the result that can be expected, taking into account the state of the sick person and his or her physical and moral resources."

## Your wish is my command

The distinction of ordinary and extraordinary means can be helpful for determining for yourself what treatments or procedures you would want used if faced with serious or terminal illness. And the distinction is also helpful if you're required to make decisions for another person. It is often the case that a person is declared incompetent, which means family members or close friends must make a decision regarding a course of treatment or the cessation of one in process. This situation is referred to as proxy consent or substituted judgment. In this case, a person is called to make a moral decision for another, keeping in mind the wishes and beliefs of the patient.

If you are competent, you may ask a spouse, parent, or sibling to be your proxy if you become incapacitated. As a proxy, a person must

**Would your doctor be willing and able to carry out your wishes?**

clearly understand the patient's wishes and follow them. "A proxy must decide from the perspective of the patient and must know the patient well and love that person," says Father Albert Moraczewski, regional director of the Pope John Center in Houston, Texas.

Father Joe Kukura, vice president of theology, mission, and ethics for the Catholic Health Association, also emphasizes the importance of designating someone as a spokesperson. "The problem is if you don't designate someone, then those around you are forced to assume that everything should be done or the courts end up deciding." Assigning a durable power of attorney means that that person retains the authority to make your health-care decisions if you become incompetent.

The Catholic Church has taught that the proxy should determine what is best by not only referring to the patient's wishes but also to the present state of related circumstances. A family member or a friend who is serving as a proxy is morally obligated to fulfill the patient's wishes as best as he or she can yet is not bound to take extraordinary measures. A proxy must take into account the overall circumstance of the patient and may determine that life-sustaining treatment be continued for the sake of the family or until pain is alleviated."

The church also teaches that it is wrong for a proxy to carry out unethical decisions, such as euthanasia, even if the patient desires it. However, the use of some narcotics for pain relief have the effect of slowing the heart rate and respiration, and thus death may ensue more quickly. But the church does not consider their use as an act of euthanasia because the intention is to alleviate pain rather than to end life.

The Vatican's *Declaration on Euthanasia* states: "When inevitable death is imminent in spite of the means used, it is permitted in conscience to make the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted."

Thus, the current teaching of the church protects against an overabuse of technological means to sustain life. Life is not to be prolonged at all costs or by every extraordinary means.

The National Conference of Catholic Bishops notes three situations where treatment would be considered extraordinary: terminal illness where death is imminent; comatose patients with no medical hope of regaining consciousness; terminal illness where neither death nor unconsciousness is imminent. In this last case, a person may stop treatment or decline surgery if these offer little substantial benefit or if the patient could become further inca-

pacitated, if death is a risk, or if extreme pain or expense is involved.

The Catholic Health Association provides Christians with a living-will document, its "Christian Affirmation of Life: A Statement on Terminal Illness." This living will puts one's requests regarding life-sustaining treatment in the context of the Christian faith. It states: "Christians believe that in death life is transformed by the power of Christ's death and resurrection into eternal life. Because of this belief it's not always necessary to use every possible means to resist death."

Kukura says, "The document is meant to assist families in discussing their various treatment options and to see the Roman Catholic tradition as a rich resource for their reflection. In today's society the technological advances make treatment decisions very complicated. A living will can help focus this discussion by allowing people to state what they want." Although this living will is not intended to be a legal document but rather a statement of moral beliefs, it may assist if legal action is necessary.

It states: "I have a right to make my own decisions concerning treatments that might unduly prolong the dying process. If I become unable to make these decisions and have no reasonable expectation of recovery, then I request no ethically extraordinary treatment be used to prolong my life but that my pain be alleviated if it becomes unbearable, even if this results in shortening my life."

## Throw it out to the group

Speaking with a spouse or a parent or one's doctor is a good place to begin making decisions about treatment, but a parish-wide discussion may also assist people in sorting out their values. Rarely do parishes meet to discuss such issues, and even more infrequent are sermons that explain Catholic teaching on life-sustaining treatment or Catholic beliefs about terminal illness and death.

Here are several suggestions to promote a discussion in your parish so that you can share your ideas, learn from others who have had a firsthand experience with terminal illness, and see what documents are available to make your wishes known:

- Invite the parish priest or an able member of the congregation to prepare a series of sermons on the theology of sickness and death.
- Invite a physician, nurse, or other health-care practitioner from the parish to lead a discussion on what life-sustaining treatment is, how people can talk with their physicians or nurses about what they want, and what specific treatments they can expect for certain conditions.
- Invite someone from a local hospital to find out what the hospital's policy is about life-sustaining treatment. Find out if the doctors at that hospital support living wills.
- Invite an attorney from your parish to speak about living-will legislation in your state. Have examples of living wills available so people can review them, especially the "Christian Affirmation of Life."

**A proxy is morally obligated to fulfill your wishes yet is not bound to take extraordinary measures.**

Robert Swidler, staff counsel for the New York State Task Force on Life and the Law, suggests three ways to stay out of Probate Court. First, families and individuals should plan in advance regardless of the legal jurisdiction or living-will laws in their home state. "Anyone who has strong feelings about treatment should put it in writing," Swidler says. If your legal jurisdiction has living-will legislation, then a written document should follow state guidelines; if no such guidelines exist, a written document should look formal and be official.

According to Swidler, "To make this document as valid as possible, it should be signed, renewed frequently, and witnessed."

Second, you should designate someone to act as your representative (proxy) if you become incompetent. In asking someone to be a representative, make clear to them what you want and be sure they know your values and beliefs. "If you are unconscious and can't make a decision, be sure somebody you are close to can," Swidler states.

Third, Swidler suggests that if you have an existing condition, ask your doctor what his or her opinions are about various forms of treatment. Ask whether he or she will give a "do not resuscitate" order on your chart. A "do not resuscitate order" (DNR) is written onto your chart by a physician; and in the event of cardiac or respiratory arrest, the health-care team would not resuscitate you. They are common in hospice programs, where terminally ill patients make decisions about the kind of death they want.

These three steps can begin the process of communicating your wishes for treatment. Experts agree that no one should make these decisions alone. Each requires personal reflection and some difficult choices. But if no one knows what you want, you could be placing your family and caretakers in an impossible situation of guessing. □